

DATE: 5/30/23

## **MEMORANDUM**

TO: The Honorable John F. Curran, Senate Minority Leader  
The Honorable Don Harmon, Senate President  
The Honorable Tony McCombie, House Minority Leader  
The Honorable Emanuel "Chris" Welch, Speaker of the House

FROM: Grace B. Hou *Grace B. Hou*  
Secretary *by [Signature]*  
Illinois Department of Human Services

SUBJECT: **2022 Illinois Autism Task Force Report**

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The Illinois Department of Human Services respectfully submits the 2022 Illinois Autism Task Force Report in order to fulfill the requirements set forth in Public Act 93-0773

If you have any questions or comments, please contact Christine Hammond, 708-310-5807.

cc: The Honorable JB Pritzker, Governor  
John W. Hollman, Clerk of the House  
Tim Anderson, Secretary of the Illinois Senate  
Legislative Research Unit  
State Government Report Center

# ***STATE OF ILLINOIS***

DEPARTMENT OF  
HUMAN SERVICES



## ***ANNUAL PROGRESS REPORT***

*State Efforts to Improve Services  
for Persons with Autism Spectrum Disorder*

*As required by PA93-773*



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**JB Pritzker, Governor**

**Grace B. Hou, Secretary**

100 South Grand Avenue, East • Springfield, Illinois 62762  
401 South Clinton Street • Chicago, Illinois 60607

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May 30, 2023

Dear Honorable Governor JB Pritzker and Honorable Members of the General Assembly:

Consistent with PA 93-773, I am pleased to submit to you the eighteenth annual progress report on efforts to improve services for persons with autism spectrum disorder (ASD) and their families.

The Illinois Autism Task Force (IATF) and its working committees have continued to work this year on behalf of persons with ASD and their families, providing valuable input and guidance to the Illinois Department of Human Services (IDHS), the Illinois Department of Healthcare and Family Services (HFS), and the Illinois State Board of Education (ISBE).

This report details progress made in several areas:

- Addressing Early Intervention services for children with autism
- Enhancing family support mechanisms to enable persons with autism to remain in their homes and communities
- Transition services from public school services; and
- The Section 1915c waiver for persons with autism

By supporting the work of this Task Force, supporting the Children's Waivers and the use of federal reimbursement for the growth of services, and supporting crucial legislative changes, you have demonstrated your interest in and continued support of this important work. We look forward to continuing to partner with you and the IATF in the future.

Sincerely,

Grace B. Hou  
Secretary

## Overview

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On July 21, 2004, Public Act 093-0773, "An Act in Relations to Persons with Disabilities", was signed into law. PA 093-0773 directed IDHS to convene a special task force, to "study and assess the service needs of persons with ASD".

This report, as required by Public Act 93-773, focuses on this year's progress relative to four specific areas:

1. Addressing Early Intervention services for children with autism
2. Enhancing family support mechanisms to enable persons with autism to remain in their homes and communities
3. Transition services from public school services; and
4. The Section 1915c waiver for persons with autism

### ***PROGRESS IN ADDRESSING FOUR AREAS REQUIRED BY PA93-773***

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- **Early Intervention Services for Children with Autism**

**The Act Early Committee:**

The Act Early Committee reconvened in July 2020 and has since been meeting monthly. The Committee determined key goals for focus in 2021. The Act Early Committee made continued progress on these goals in 2022:

- Understand challenges in providing autism specific interventions in Early Intervention and identify solutions to support suitable interventions for children at risk of ASD, including behavior therapy.
  - Early Intervention, before age three, is especially beneficial to improve long term outcomes due to the neuroplasticity of the brain before the age of 3. Identification and intervention before the age of 3 can have transformative and exponential effects on child's developmental trajectory.
  - The group will work to identify opportunities to deliver ASD specific interventions to children at risk of ASD during the time period from EI enrollment to the receipt of formal medical diagnosis, as medical diagnosis wait-lists are long and medical diagnosis often occurs close to the 3<sup>rd</sup> birthday.
  - Identified opportunity: Many children are recognized as being at risk for autism diagnosis months before they receive the actual diagnosis. Target this interim period for interventions as noted above. Often, children are not receiving autism specific interventions, and important intervention opportunity is lost.
  - The Committee is utilizing published best practices from national expert groups to create a new "checklist" and quick reference guide that service coordinators and other

providers in Early Intervention (IDEA Part C) can refer to once a child is identified as being at risk of an autism diagnosis in order to ensure that the appropriate interventions are implemented.

- Very few BCBAs, who are trained in evidence-based behavior interventions for autism, are credentialed in Early Intervention (IDEA Part C).
- Investigate opportunities for additional ASD/universal screening when a child is referred to Early Intervention and make recommendations to Early Intervention for implementation of screening process.
  - Identify and implement strategies to improve the referral process to Early Intervention by primary care providers, including examining communication between primary care providers and early intervention providers. The Illinois Chapter of American Association of Pediatricians has formed a task force to promote collaboration and communication between primary care physicians and Early Intervention providers. The Act Early Committee is collaborating with ICAAP to promote quality referrals to Early Intervention and Special Education services.
  - Determine how to best support primary care and EI providers to have difficult conversations with parents and caregivers to avoid “wait and see approach” and deploy identified support strategies.
  - Identify and deploy strategies to increase primary care and Early Intervention provider knowledge about ABA scope and indications to improve service referral and delivery.
  - Investigate and implement ways to support transition from EI to Early Childhood Education programming.
- The Act Early Committee’s Completed Work in 2022:
  - Partnered with the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) scholars to survey credentialed Board-Certified Behavior Analysts (BCBAs) in EI and a those that are not to determine how to engage more BCBAs in Early Intervention system. Identified barriers to credentialing hours and mentorship as barriers to engaging BCBAs in Early Intervention.
  - LEND scholars, working with committee members, investigated other states’ processes and protocols to identify children at risk of ASD Early Intervention (Part C) programs and identify barriers and opportunities other stated have addressed.
  - Drafted initial guidance document for Early Intervention Checklist for children identified to be at risk for Autism Spectrum Diagnosis.
  - Partnered with the Illinois Chapter of the American Academy of Pediatrics (ICAAP) Early Childhood Committee to develop a survey to assess and identify barriers to pediatrician and Early Intervention (Part C) communication and impacts on early identification and provision of services.
- The Act Early Committee Action Plans for 2023:
  1. In partnership with the LEND scholars, the Act Early Committee will continue to finalize the guidance document, visual checklists, and reference items needed to implement a new intervention checklist for children identified to be at risk of an autism diagnosis.

2. Partner with Illinois Chapter of the American Academy of Pediatrics and the Illinois Academy of Family Physicians to address barriers to early identification with re-invigorated information campaigns:
  - a. Improved communication between referring pediatricians, parents, and Early Intervention using the preferred referral forms.
  - b. Increasing pediatrician and family physician understanding of the referral process and services provided by home visiting and early intervention.
  - c. Increase awareness and promote parent education in developmental monitoring, using the CDC Learn the Signs, Act Early Campaign materials.
  - d. Promote awareness of Medicaid coverage of ABA to primary care to increase access to this valuable therapy option for families utilizing public insurance.

- **Enhancing Family Support Mechanisms to Enable Persons with Autism to Remain in Home-based or Community Environment.**

- Updates on the Support Service Teams (SST's) and related information can be found on the DHS website <http://www.dhs.state.il.us/page.aspx?item=50861> or <http://www.dhs.state.il.us> under the Division of Developmental Disabilities' link.
- IDHS DDD has implemented movement from the PUNS list into a DD Waiver service at a "Reasonable Pace". This means that individuals in the Seeking Services category will be selected from the PUNS list annually, as appropriations allow. Selections will be based on a person's cumulative length of time in the Seeking Services category after their 18<sup>th</sup> birthday (i.e., those with the most months accumulated are selected first).
  - In Fiscal Years FY20 the DDD agreed to serve an average minimum of 600 individuals from the PUNS list for the years. In FY21 through FY25, the DDD agreed to serve a minimum of 630 individuals from the PUNS list each year. This multi-year plan has an end goal such that by FY25, the maximum wait time for the PUNS list will be 60 months or 5 years. ISCs will continue to submit funding requests for eligible individuals who are determined to be in crisis (homeless, abused or neglected), these individuals will not wait for PUNS selection.

- **Adequate Transition Services for People with Autism from Public School Programs to Adult Services.**

#### **The Autism Task Force Transition Subcommittee**

Transition Planning is an important process that is a part of every student's IEP starting at age 14½. The format and information that is provided to parents and students regarding transition varies greatly across the state. Parents and Professionals who attend IATF meetings have voiced concerns that the information provided to parents and students across the state is inconsistent and lacking in some areas. Therefore, parents and students are not getting all the information needed to plan and may be missing opportunities that otherwise would be available to them if they were better informed.

The Autism Task Force Transition subcommittee in 2022 developed a survey tool to assess parent/family knowledge when it comes to understanding services available for the autism population during their high school transition years. By gaining understanding of this, the IATF, as well as autism-based services entities and schools can target their messaging and parent education to better guide parents and families with the goal of improving student success post high school.

The ATF Transition sub-committee developed the survey tool to tentatively go live in the Fall of 2023 to assess parent/guardian knowledge of the transition process as well as all the services and supports involved to ensure post high school success. The launch of the survey was coordinated with ISBE so as not to interfere with the ISBE annual indicator 8 parent/guardian survey.

The sub-committee plans to collaborate with other entities around the state in order to disseminate the survey with the goal of obtaining a diverse geographic response rate.

### **Employment First**

The Co-chairs of the IATF Transition subcommittee remain active members of the Employment and Economic Opportunity for People with Disabilities (EEOPD) Transition Workgroup.

### **Adult Services Subcommittee**

The Adult Services Subcommittee was formed in 2021 and began work in March 2021. The IATF formed the Adult Services Sub-committee with the intent to focus more attention on the needs of individuals post high school and beyond who continue to experience barriers to services and supports.

The Adult Services Subcommittee areas of focus for 2022:

- **Community Day Services:** expanding the options for people with autism on either end of the spectrum. Individuals with autism who have not been diagnosed with an intellectual disability or who do not meet the requirements for a related condition are not eligible for services under the HCBS Waiver. CILA residents can only direct their waiver funding to state-licensed residential programs. There are barriers for meeting employment needs for these individuals and utilizing their skills. Frequently, this is a consequence of not being able to adequately support individuals whether it be transportation or staffing. The goal is to make sure the individual has the supports over the long term to engage in the community and offer flexibility in how individuals can structure their own day, whether it be for work or leisure.
- The Subcommittee researched self-directed services in other states which led to a focus on states offering Community First Choice Option Section 1915 (k) waivers. Nine states offer services and supports under the Community First Choice state plan option, five of those states are State Transition Plan leaders obtaining CMS's final approval of their Statewide Transition Plans under the Settings Rule.
- The Sub-committee's work coincides with the state's implementation of the Settings Rule statewide transition plan in March 2023. The sub-committee plans to share their findings with the IDHS Division of Developmental Disabilities (DD) as an informational presentation while DD under the HCBS Settings Rule continues to develop and seek methods to assure people receiving services have access to community living that meets their needs and is of their choosing.

## **Insurance Subcommittee**

In 2022 the Autism Insurance Sub-Committee divided into two groups; one group focused on young children, the other on adults.

- The children's insurance group developed the following goals:
  - Early as possible diagnosis- Early diagnosis leads to valuable services at an earlier age
  - Diagnostic services are adequately covered by insurance (private and public)
  - Adequate numbers of providers available to provide diagnostic services
  - Providers receive fair reimbursement for diagnostic services under insurance including Medicaid
  
- A plan was created to reach the goals established:
  1. Define barriers for diagnosis
  2. Ask for data information to get a snapshot of waiting lists vs. capacity
  3. Map of state sites providing diagnostic services
  4. Set forth a plan/recommendation to address those gaps and define who had the most impact in correcting these gaps
  5. Report to the DHS Secretary
  
- To begin work on #'s 1 and 2 the sub-committee compiled a list of providers throughout the state who complete diagnostics and their geographic locations.

Next Steps:

The Autism Insurance Sub-Committee will collect voluntary data on provider's waiting lists and capacity to develop a snapshot of statewide needs vs. the capacity of providers to make diagnosis. We would like to assess to the extent possible where the gaps are rural vs. urban, private insurance vs. Medicaid in children getting diagnosed.

1. Survey Providers on waitlist numbers based on age
2. Survey Providers on annual capacity of diagnostic services

The Adult Insurance group met once during this reporting period to develop priorities. the group is working to establish leadership to support this sub-committee.

The IATF Insurance Sub-committee is ABA therapy still deeply committed to ABA therapy being accessible to Medicaid recipients with autism. We will continue to support this and collaborate with autism advocates to pursue this goal. Autism advocates are continuing the work to promote this through legislative channels.

## **Partner Accomplishments- Calendar Year 2022**

- For 2022 The Autism Program of Illinois (TAP), along with its statewide network partners produced the following deliverables: TAP conducted 4 (two-day) virtual Autism Diagnostic Observation Schedule (ADOS-2) Clinical Training workshops for professionals during fiscal



year 2022 continuing to build capacity for future diagnosticians in Illinois. One hundred sixty-seven (167) professionals were trained in the ADOS-2 throughout the fiscal year, which remains the gold standard instrument in the diagnosis of ASD. Clinical training workshop attendees included school psychologists, clinical psychologists, occupational therapists, speech and language therapists, behavioral therapists, and pre-professional clinicians from those domains.

- TAP completed 648 ASD-specific screenings and 474 ASD-specific diagnostic evaluations during fiscal year 2022.
- Nine expert-led trainings were conducted by TAP in fiscal year 2022. Expert-led trainings consisted of four ADOS-2 clinical workshops, four trainings conducted during the second annual TAP Autism Symposium, as well as one expert-led Board Training for TAP network partners interested in receiving professional educational support for their board of directors. Two-hundred ninety-six (296) individuals in Illinois benefitted from the expertise shared during these expert-led trainings.
- TAP conducted the second annual (virtual) Autism Symposium featuring state and national autism experts during April of fiscal year 2022. Keynote speaker, Wayne Fisher, Ph. D., BCBA-D, presented on recent advances in the functional analysis and treatment of severe destructive behavior. Autism experts from TAP university partners Southern Illinois University Carbondale, University of Illinois Urbana-Champaign, and the University of Illinois Chicago also provided educational sessions during the symposium. Topics included applying behavioral systems analysis to improve inter-professional collaboration, using tele practice to build capacity within communities, and innovative approaches to assessing and treating life skills deficits in individuals with autism. Eighty-six (86) professionals and community members from all parts of the state attended the all-day symposium.
- TAP conducted 763 trainings for professionals serving 9,987 participants comprised of educators, early intervention providers, medical professionals, behavioral health providers, first responders, and pre-professionals working in the field. Topics included: understanding neurodiversity, social skills in early childhood, utilizing visual strategies and visual supports for social emotional learning, transition topics, trauma informed care, managing challenging behavior and preventing and managing crises, disability experience in healthcare, disability and victimization, and sexuality and disability. Notably, four QBS Safety-Care® training sessions were conducted for rural Head Start teachers, paraprofessionals, and staff in southern Illinois to learn how to prevent and manage crises utilizing effective strategies from Applied Behavioral Analysis (ABA) and Positive Behavior Interventions & Supports (PBIS). Additionally, five Crisis Intervention Training (CIT) sessions were conducted for 250 correctional officers during the fourth quarter.
- TAP conducted fifty-nine (59) trainings for parents, families, caregivers, and individuals on the autism spectrum, serving a total of 1,160 individuals throughout Illinois. Topics covered included: understanding autism, new diagnosis training, teaching safety skills, toilet training, teaching social skills in the home, strategies to teach reading at home, and parent sessions to prepare students with autism and their families for transition to post-secondary education. Many trainings were conducted in both Spanish and English to reach a broader demographic throughout the state.
- A total of 996 group sessions were conducted in fiscal year 2022, serving 2,376 individuals across the state. TAP network partners continued to provide social skills groups utilizing the

evidence-based PEERS® curriculum, both virtually and in-person with concurrent parent support groups to generalize the skills learned and maintain student progress. During groups, preschool children learned language and social skills, teens and young adults benefited from learning life skills such as cooking, and college students, ages eighteen through twenty-one with autism, benefited from learning how to deal with transitions, setting schedules, and improving executive functioning skills. Specific social skills groups for girls with autism were also provided to meet the unique needs of this neurodiverse demographic. Several summer camps for children with autism were provided by TAP network partners during the fourth quarter as well. Finally, many group sessions were conducted in Spanish and English during the fourth quarter of FY 2022 for Latino families in order to provide learning opportunities about autism spectrum disorder, evidence-based interventions, to learn about the disabilities service system in Illinois and the many services and supports provided throughout the state.

- TAP provided 18,332.34 hours of evidence based ASD interventions to a total of 939 individuals in fiscal year 2022. Evidence-based autism interventions included ABA therapy, counseling, speech and language therapy, occupational therapy, physical therapy, assistive technology support, and job skills training. Notably, during the fourth quarter, evidence-based interventions also included push-in classroom services provided to Head Start students in rural southern Illinois, providing much needed speech language therapy and behavioral therapy to underserved students.
- During fiscal year 2022, TAP provided a total of 4,084.65 hours of consultation through the Family and Community Resource Rooms (FCRRs) to 1,123 individuals comprised of family members, caregivers, educators, and various professionals throughout the state. TAP served a total of 12,189 Illinoisans through the Family and Community Resource Rooms (FCRRs) during fiscal year 2022. Although two of TAP's FCRRs remained closed due to Covid restrictions, TAP network partners continued to make resources available digitally, via appointment, and continued to create customized visual supports and materials for educators, parents, caregivers, service providers, and community members disseminating them via curbside pick-up, delivery, and by mail.
- During fiscal year 2022, TAP network partners received and responded to 942 requests for autism services submitted by individuals and/or families through the Signify Health platform that is available on the TAP website. TAP network partners continue to make outreach and follow up with parents, guardians, and individuals requesting autism services, connect them with appropriate services at their TAP site, make referrals to other TAP network providers as appropriate, and connect individuals and families with local community resources as well as statewide resources that best address their unique needs.
- The TAP network participated in a total of 425 collaborations with state and national level agencies and organizations during FY2022. TAP continues to collaborate with The Arc of Illinois and actively participates in the Illinois Autism Task Force, including committee participation on the Illinois Autism Insurance Sub-Committee and the ACT Early Sub-Committee. TAP network partners continue to work with educators and staff from local Head Start providers, school districts, regional offices of education, and special education departments quarterly to provide linkage for autism services and resources and to provide training, education, and consultation for educational providers working with students with autism or suspected of having autism spectrum disorder. On a national level, TAP network partners collaborated with the Association of Speech and Hearing Association (ASHA), and the

All Our Kids Network and served on the national Human Trafficking Task Force Training Subcommittee as well as the National Human Trafficking and Disabilities Working Group during quarter four of fiscal year 2022. Additionally TAP network partners worked with local disability service providers in their regions as well as the ECHO Autism Telemonitoring series to provide case consultation and collaborative learning opportunities throughout the year. TAP network partners continue to collaborate with local medical providers and behavioral health providers in order to streamline referrals for autism screenings and diagnostic evaluations and to reduce waitlist times to better serve families seeking these services in Illinois.

- **Feasibility of obtaining federal financial participation and obtaining a Section 1915c waiver for persons with autism.**

The Division of Developmental Disabilities continues to operate and receive federal financial participation on three 1915c Medicaid Home and Community-Based Services (HCBS) Waivers for children and young adults with developmental disabilities (including children with autism). The Children's Support Waiver, the Children's Residential Waiver and the DD Adult Waiver were all approved with an effective date of July 1, 2022. The most recent Waivers are available at <https://www2.illinois.gov/hfs/MedicalClients/HCBS/Pages/default.aspx>

In addition to the specific service options outlined below, each individual in a DD Waiver program receives case management from an Independent Service Coordination (ISC) Agency. ISC agencies serve as the front line for information and assistance to help individuals and families navigate the DD system and to ensure individual's health, safety, welfare, well-being, and satisfaction with services funded by DDD.

### **Children's Support Waiver**

The Children's Support Waiver serves children and young adults (age 3 through 21) with developmental disabilities (including children with autism) who live at home with their families. Families are given a monthly allotment to purchase needed services.

Available service options:

- Personal Support (includes in-home respite in definition)
- Self-Directed Assistance (assist the family in arranging for, directing, and managing services)
- Temporary Assistance
- Behavior Intervention and Treatment
- Training and Counseling for Unpaid Caregivers
- Home/Vehicle Modifications

The maximum unduplicated number of participants for the Children's Support Waiver was 898 at the end of FY22. New enrollees will be selected from the PUNS database when there are appropriations in the state budget or enter service as a crisis (homeless, abuse or neglected). The Children's Support Waiver is designed to be similar to the adult Home-Based Support Services in the DD Adult waiver. This facilitates a seamless transition to adult Home-Based Supports, should these services be needed for young adults between the ages of 18 and 21.

Services are specified in each individual's Personal Plan and HBS Service Agreement. Services are limited each month to not exceed the monthly allotment which is two hundred percent (200%) of the monthly federal Supplemental Security Income (SSI) rate. The Waiver cost limit is adjusted annually at the start of each calendar year based on cost-of-living changes in the federal SSI payment levels.

### **Children's Residential Waiver**

The Children's Residential Waiver provides residential habilitation in a licensed child group home for children and young adults (ages 3 through 21) with developmental disabilities (including children with autism) that require this service. Child Group Homes are licensed by the Illinois Dept. of Children & Family Services (DCFS).

Covered Services include:

- Residential habilitation
- Behavior Intervention and Treatment

The maximum unduplicated number of individuals served in the Children's Residential Waiver was -152 FY22.

Services are designed to be similar to residential services in the DD Adult waiver to facilitate a seamless transition to adult waiver services for individuals between the ages of 18 and 21, should these services be needed.

### **Overview of 2022 Waiver Activities**

Annually, IDHS reviews a variety of waiver quality assurance performance measures. Results are shared with the HFS and the federal CMS. The compliance results are posted on the Division's website at: [IDHS: Developmental Disabilities Reports \(state.il.us\)](https://www.idhs.gov/developmental-disabilities-reports) (see Medicaid Waiver Reports)

## ***ILLINOIS AUTISM TASK FORCE MEMBERSHIP***

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*Ms. Kruti Acharya, University of Illinois-Chicago LEND*

*Ms. Patti Boheme, Wellspring Clinical Associates- Co-Chair of the IATF, and Co-Chair of the Transition Sub-committee\**

*Ms. Sasha Boheme, Hinsdale Township High School*

*Ms. Amanda Brott, The Hope Learning Academy*

*Ms. Stephanie Brown, Parent, the Autism Society Southern Illinois*

*Ms. Sherry Brueck-Ladislas, Parent, Trinity Services*

*Ms. Mo Buti, Aiepa Advocate, and Instructional Expert for People with Autism*

*Dr. Nasiah Cirincione-Ulezi, Ulezi, LLC*

*Ms. Amy Cohen, University of Illinois Autism Clinic*

*Mr. Brian Dacy, Rehab Tech Supply*

*The Honorable Peter "Pete" DiCianni, Parent, DuPage County Commissioner of the 2nd District, former Mayor of Elmhurst– Co-Chair of the IATF, Chair of the Insurance Sub-committee\**

*Dr. Tom DiMatteo, Wellspring Clinical Associates*

*Mr. Anthony G. DiVittorio, Clearbrook*

*Ms. Theresa Forthofer, Easter Seals-DuPage, Fox Valley*

*Dr. Karen Fried, Sonia Shankman Orthogenic School*

*The Honorable Sara Feigenholtz, State Senator- 6<sup>th</sup> District*

*Ms. Candice Gizewski, Behavioral Perspective Inc.*

*Dr. Ramiro Gumuccio, Parent*

*The Honorable Don Harmon, State Senator – 39<sup>th</sup> District*

*Ms. Sherry Healey, Parent- Chair of the Adult Services Sub-committee\**

*Mr. Terry Herbstritt, Parent, PACTT Foundation*

*Mr. Charles-Eugene Jiongco, Behavioral Perspectives*

*Ms. Kiya Olson, ASPB Therapy Pathways*

*Ms. Matiana Ovalle, Parent, UIC and Grupo-Salto*

*Ms. Zoubida Pasha, Parent, Family Resource Center on Disabilities- Co-Chair of the Transition Sub-committee\**

*Ms. Megan Roberts, Northwestern University*

*Ms. Cari Roestel, Act Early Ambassador- Chair of the Act Early Sub-committee\**

*Ms. Colleen Shinn, Autism Speaks*

*Ms. Ruth Ann Sikora, Parent, Comprehensive Services Committee*

*Ms. Debra Vines, The Answer*

*\*Co-chairs of the Task Force and Subcommittees*

## ***II. STATE AGENCY PARTNERS***

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*Christine Hammond, Department of Human Services – Office of the Assistant Secretary -Programs*

*Nkechi Onwuameze, Illinois State Board of Higher Education*

*Sarah Myerscough-Mueller, Department of Human Services-Division of Developmental Disabilities*

*Sean P. Weldon, Department of Human Services-Division of Rehabilitation Services*

*Dr. Constance Williams, Department of Human Services – Division of Mental Health*